Respect, trust, and the management of sickle cell disease pain in hospital: Comparative analysis of concern-raising behaviors, preliminary model, and agenda for international collaborative research to inform practice

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Cite as: Elander, J., Haywood, C., & Beach, M.C. (2011). Respect, trust, and the management of sickle cell disease pain in hospital: comparative analysis of concern-raising behaviors, preliminary model, and agenda for international collaborative research to inform practice. *Ethnicity and Health*, 16 (4-5), 405-421. DOI: 10.1080/13557858.2011.555520.

Abstract

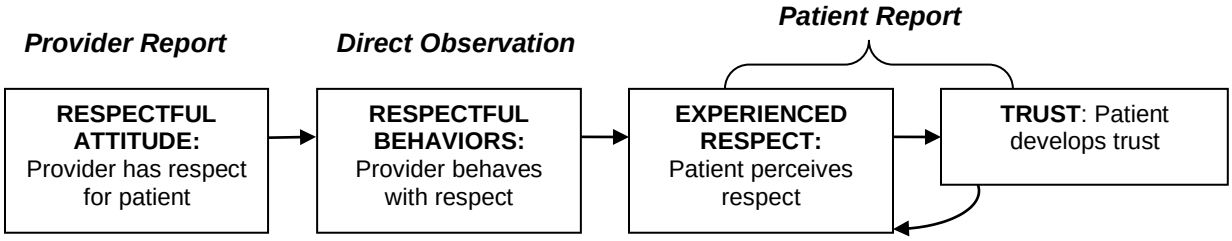
Background/objectives: Qualitative interview studies suggest that adult patients' experiences of hospital treatment for sickle cell disease (SCD) pain reflect an absence of respect by providers for patients, and an absence or breakdown of trust. Systematic comparisons between treatment settings could help identify contextual influences on respect and trust.
Design: Quantitative comparison of concern-raising behaviors (pain treatment outcomes indicating breakdowns of trust) among adult SCD patients in Baltimore, Maryland, U.S.A., and London, U.K., followed by analysis of potential explanations for differences, including socio-cultural and behavioral factors, with a preliminary model of the processes leading to concern-raising behaviors.
Results: Rates of concern-raising behaviors were significantly higher in Baltimore than London. The model identifies respect and trust as key factors which could be targeted in efforts to improve the quality of SCD pain management in hospital.
Conclusion: An agenda for international, interdisciplinary research to improve the treatment of SCD pain in hospital should include: comparative analyses between countries and treatment settings of factors that could influence respect and trust; research to test hypotheses derived from models about the roles of respect and trust in the treatment of pain; studies of the impact of healthcare structures and policy on patients' experiences of care; research focusing on developmental and interpersonal processes related to respect and trust; applications of attribution and other social psychology theories; and development and evaluation of interventions to improve the hospital treatment of SCD pain by increasing respect and trust.

Keywords: respect, trust, SCD pain, concern-raising behaviors, hospital treatment.

Introduction

Respect is an attitude of valuing another person, and is demonstrated by behaviors that express that attitude (Beach *et al*. 2007). Trust develops in relationships, in part due to the presence of respect. In relationships between healthcare providers and patients, respect and trust develop in a process that begins with providers' attitudes towards patients, which are reflected in provider behaviors when interacting with patients. Patients' experiences of those behaviors, and their perceptions and beliefs about their treatment, then contribute to the degree of trust between patient and provider, which in turn influences how subsequent behaviors are interpreted. Figure 1 shows a simplified model of the relationship between respect and trust and the ways they are usually measured.

Figure 1. The relationship between respect and trust



Patients can judge fairly well how much respect their physicians have for them, for physicians offer more information and express more positive affect towards patients for whom they report having more respect (Beach *et al*. 2006), and physicians' ratings of how much they like and respect their patients are related to patients' ratings of how well they are treated and how satisfied they are with their care (J.A. Hall *et al*. 2002).

Trust in the context of healthcare has been examined mainly from the perspective of patients' trust in healthcare providers, with much less research about providers' trust in patients, although that is also important. Self-report measures have been used to measure patients' trust in individual providers (M.A. Hall *et al*. 2002), and in healthcare systems, hospitals or physicians in general (Rose *et al*. 2004). In both cases, 'trust' means a patient believes the provider will act in their interests, whereas mistrust or distrust, which are not simply the absence of trust, mean that a patient believes they may be hurt or harmed by the provider (Rose *et al*. 2004). Across a range of settings and medical conditions, patient reports of respect and trust are associated with satisfaction with care, continuity of care, adherence to therapy, and preventative health behaviors (M.A. Hall *et al*. 2002, Beach *et al*. 2005).

In Western countries, respect and trust are lower for patients who are members of minority ethnic groups. In one study of physicians' attitudes, African American patients were rated more negatively, compared with white patients, in intelligence, educational level, adherence with medical advice, and likelihood of abusing drugs and alcohol, even after controlling for many of those factors (Van Ryn and Burke 2000). Observational studies of physician-patient interactions with African American and white patients have shown that, with African American patients, physicians were more verbally dominant (Beach *et al*. 2011), used a more negative emotional tone (Johnson *et al*. 2004), adopted a more narrowly biomedical communication style (Roter *et al*. 1997), exhibited less nonverbal attention, empathy, courtesy

and information-giving (Hooper *et al*. 1982), and spent less time chatting, answering questions, and providing health education (Oliver *et al*. 2001).

Less respectful provider behavior when interacting with patients belonging to minority ethnic groups has been found across many medical conditions and types of treatment, and may contribute to systematic inequalities in quality of care and health outcomes (Van Ryn & Fu 2003). This includes the treatment of pain, for patients who belong to minority ethnic groups have been shown to receive poorer pain management across a range of different treatment settings (Green *et al*. 2003), including hospital emergency departments (Todd *et al*. 1993).

Acute episodes of vaso-occlusive pain are the most common reason for hospital treatment among people with sickle cell disease (SCD), but treatment for SCD-related pain often falls short of that recommended in established treatment guidelines (National Institutes of Health 2002), and there is considerable evidence about under-treatment of SCD pain (Haywood *et al*. 2009). Patients with SCD rated the quality of their treatment in hospital lower than did a national sample of adults (Lattimer *et al*. 2010), and SCD patients' reports of poor communication with healthcare providers were associated with less trust in providers (Haywood *et al*. 2010).

Qualitative methods have been used in a number of studies to explore SCD patients' experiences of hospital pain management, including five conducted in the U.K. and three in the U.S.A., whose key features are summarized in table 1. The key themes reported from those studies focus almost exclusively on interpersonal aspects of pain management, rather than analgesic methods or types, and are highly interpretable in terms of an absence of respect and trust. There is considerable convergence between studies, with negative experiences predominating in both countries and no striking differences between patients' experiences in the U.S.A. and U.K.

Table 1. Qualitative studies of SCD patients' experiences of hospital pain management (in alphabetical order by author)

Study	Country	Sample	Methods	Key themes
Alleyne and Thomas (1994)	U.K.	10 SCD patients and10 hematology nurses	Semi-structured interviews and focus groups	• Poor pain management • Anxieties about pethidine • Loss of/lack of control • Lack of individualized care • Playing up
Booker *et al*. (2006)	U.K.	10 SCD patients	Focus groups	• Dealing with healthcare professionals 'like a battle' • Need to convince doctors of legitimacy of pain • Poor provider knowledge of SCD
Butler and Beltran (1993)	U.S.A.	10 sessions with 8 to 24 SCD patients, family members, and physicians	Description of patient educational sessions	• Denial of care by physicians • Physician suspicion and distrust • Lack of patient involvement in care
Harris *et al*. (1998)	U.K.	27 SCD patients	Structured interviews	• Mistrust and negative attitudes from providers • Rude treatment by providers • Lack of provider appreciation of patient pain
Maxwell *et al*. (1999)	U.K.	57 SCD patients	Semi-structured interviews and focus groups	• Mistrust of patients by staff • Stigmatization • Excessive control • Neglect
Shelley *et al*. (1994)	U.S.A.	11 SCD self-help group leaders	Structured interviews	• Delays, staff training, and staff turnover in the emergency room (ER) as problematic for patients • Administration of analgesics and provider fears of drug addiction • Negative attitudes of physicians toward patients who tried to be involved in their own care
Strickland *et al*. (2001)	U.S.A.	10 SCD patients and 11 family members	Focus groups	• Stigmatization by health care providers • Negative attitudes of health care providers leading to poor pain control • Providers intimidated by patients showing knowledge of disease
Thomas and Taylor (2002)	U.K.	17 SCD patients	Focus groups	• Hospitalization as disruptive to life • Negative attitudes of some hospital staff • Importance of staff showing care and concern • Lack of staff understanding/empathy for pain

Comparative analysis of concern-raising behaviors

Rationale

One approach to investigating problematic pain management in SCD was to define criteria for 'concern-raising' events and behaviors, which are objective indicators that pain management has not been successful and that patient-provider trust has broken down. Elander *et al*. (2004) defined five in-hospital concern-raising behaviors:

- Staff-patient disputes about pain or analgesic requirements
- Patients being accused or suspected of analgesic misuse
- Patients using analgesics other than those prescribed
- Patients tampering with analgesic delivery systems
- Patients self-discharging or departing abruptly from hospital

Systematic comparisons between treatment settings could provide insights into ways that contextual factors influence respect and trust, and we compared rates of concern-raising behaviors between two large cities in two continents: Baltimore, Maryland, U.S.A., and London, U.K. The aim was to identify differences between settings to use as a starting point for theorizing about the influence of contextual factors on respect and trust.

Methods

In London, the data were collected in a patient interview study described previously (Elander *et al*. 2004). SCD patients attending large, inner city clinical centers were interviewed about experiences of pain management. The sample was 51 adult patients (17 (33%) male, 34 (67%) female), with a mean age of 34 years (SD 10 years). There were 38 (75%) with hemoglobin genotype Hb SS, and 13 (26%) with Hb SC or Hb SBeta Thal. Pre-established criteria for each concern-raising behavior were applied, and inter-rater reliability was demonstrated by Kappa coefficients ranging from 0.63 to 0.82 (Elander *et al*. 2004).

In Baltimore, the data were collected similarly. The sample was 95 adult patients (39 (41%) male, 56 (59%) female), with a mean age of 32.8 years (SD 10.47 years). There were 60 (64%) with hemoglobin genotype HbSS, and 30 (32%) with Hb SC or Hb SBeta Thal.

Results

Table 2 shows lifetime prevalence rates of concern-raising behaviors, and tests of differences between cities. The rates were high in both cities, with over three-quarters of patients in Baltimore and over half those in London reporting at least one concern-raising behavior, suggesting that problematic hospital pain management is an international problem. The overall rates and those for three of the five concern-raising behaviors were significantly higher in Baltimore than London. The differences were especially marked for tampering with analgesic delivery systems, where the Baltimore rate was eight times higher than in London, and self-discharge from hospital, where the rate was three-and-a-half times higher.

Table 2. Numbers of patients (%) reporting in-hospital concern-raising behaviors (CRBs) in Baltimore and London

Concern-raising behavior	Baltimore, U.S.A. (n=91)[a]	London, U.K. (n=51)	P
Disputes with staff	60 (66%)	20 (39%)	0.002[b]
Suspected/accused of analgesic misuse	28 (31%)	10 (20%)	0.149[b]
Using analgesics apart from those prescribed	8 (9%)	2 (4%)	0.277[b]
Tampering with analgesic delivery systems	29 (32%)	2 (4%)	<0.001[b]
Self-discharge from hospital	44 (49%)	7 (14%)	<0.001[b]
At least one concern-raising behavior	72 (79%)	30 (59%)	0.01[b]
Mean (SD) CRBs per patient	1.85 (1.39)	0.80 (0.80)	<0.0001[c]

a. Sample size less than 95 because of missing values for outcomes of interest
b. Chi Square tests
c. Independent groups T-test

Discussion

Differing rates of concern-raising behaviors suggest that contextual factors could have an important influence on respect and trust, although this comparison has a number of limitations. First, the two patient populations were not selected in advance, and may differ in ways that could affect rates of concern-raising behaviors. Second, both settings were large, westernized cities, so the results would probably not generalize to settings such as in Africa or the Caribbean. Third, data was collected at one setting several years after the other, so changes in care for patients with SCD could have affected the comparison. However, the differences provide a useful starting point for theorizing about factors that could influence concern-raising behaviors, and the rest of this paper is concerned with exploring the implications of possible explanations for differences in rates of concern-raising behaviors between settings.

Potential explanations for inter-city differences in concern-raising behaviors

There is probably no single explanation for differing rates of concern-raising behaviors; multiple factors are almost certainly involved. However, identifying potential explanations helps with theorizing about the development of respect and trust. In this section we begin with socio-cultural factors, and then consider psychological and behavioral processes that could mediate and/or moderate those factors.

National epidemiology of SCD and healthcare service delivery

Table 3 shows that there are about eight times as many people with SCD in the U.S.A. compared with the U.K., whereas the total population is only about five times larger, so the prevalence (numbers of affected individuals as a proportion of the total population) is higher in the U.S.A., with a prevalence ratio (U.S.A. prevalence divided by U.K. prevalence) of 1.59. Table 4 shows that there are also about eight times as many hospital admissions for SCD in the U.S.A., but the admission rate (SCD admissions as a proportion of the total hospital admissions) is higher in the U.S.A., with an admission rate ratio (U.S.A. admission rate divided by U.K. admission rate) of 2.53.

The difference between the U.S.A.–U.K. prevalence ratio (1.59) and admission rate ratio (2.53) seems to suggest that people with SCD are more likely to be admitted to hospital in the U.S.A. than in the U.K. This might occur because people with SCD in the U.S.A. are more severely affected, or are more willing or able to attend hospital, although people with SCD in both countries manage most painful episodes at home, seeking hospital treatment only when they are unable to manage pain at home (Thomas and Taylor 2002, Smith *et al*. 2008).

Table 3. Incidence and prevalence of SCD in the U.S.A. and U.K.

	U.S.A.	U.K.
Total population	309 million[1]	61.4 million[2]
Incidence	1/2500 – 1/2000 births[3]	1/2000[4]
Estimated SCD population	100,000[5]	12,500[6]
SCD prevalence (per million population)	323.62 per million	203.58 per million
Prevalence ratio (95% CI)	1.59 (1.56, 1.62)	Reference
P value	<0.0001	

1. U.S. Census Bureau (2008).
2. Office for National Statistics (2010).
3. Kaye *et al*. (2006).
4. Streetly *et al*. (2009). [Rates for England, not U.K.]
5. Hassell (2010).
6. Streetly *et al*. (1997).

Table 4. Hospital admissions for SCD in the U.S.A. and U.K. 1998-2007

	U.S.A.[1]	U.K.[2]
Mean SCD admissions*	79,324	9,879
% of total country admissions	0.211	0.083
Mean SCD admission rate per 100,000 admissions	210.80	83.09
Admission rate ratio (95% CI)	2.53 (2.51, 2.55)	Reference
P value	<0.0001	

* Data for hospital admissions with sickle cell disease as the principal diagnosis

1. Agency for Healthcare Research and Quality (2010).
2. Health and Social Care Information Centre (2010).

In the U.S.A., 72.8% of all SCD-related inpatient admissions are via emergency departments (Steiner and Miller 2006), so it is possible that those types of admission are more common in the U.S.A. than the U.K. Patients admitted via emergency departments could be more severely affected by SCD, with more painful crises necessitating emergency hospital treatment, or might be less well organized individuals, with more psychosocial problems and poorer coping skills, making them more likely to engage in concern-raising behaviors. Providers in emergency departments may also differ from those in other hospital departments, seeing fewer SCD patients than providers in specialist hematology wards, and having less experience and knowledge of SCD pain, leading to attitudes and beliefs that are less conducive to respect and trust. For example, attitudes towards SCD patients were more positive among inpatient providers than those in the emergency department (Ratanawongsa *et al*. 2009) and, compared to hematologists, emergency department physicians overestimated SCD patients' dependence on pain medication, and underestimated the duration of painful episodes (Shapiro *et al*. 1997).

Differences in healthcare funding could also play a role. In the U.S.A., patients with SCD are more likely than other patients to require Medicaid, and less likely to have private medical insurance, which could contribute to stigmatization (Agency for Healthcare Research and Quality 2010). In the U.K., by contrast, almost all SCD patients receive healthcare through the National Health Service, and a very small proportion have hospital treatment paid by private healthcare insurance.

Ethnicity demographics and SCD prevalence

The ethnic groups most affected by SCD are African Americans in the U.S.A. and people with African and Caribbean family origins in the U.K. (Sickle Cell Disease Guideline Panel 1993, Hickman *et al*. 1999). Table 5 shows those groups as proportions of the total national and city populations. They are minorities in both countries, but whereas African Americans make up about 13% of the total U.S.A. population, people with African and Caribbean family origins make up only 2% of the total U.K. population. At city level, however, people of African and Caribbean descent are minority groups in London, together comprising about 11% of the city population, whereas in Baltimore, African Americans are a majority, comprising nearly two-thirds of the city population. There is research showing that 'ethnic group density' is associated with better mental and physical health, possibly because of the psychological benefits associated with greater social support and reduced stigma and cultural isolation (Pickett and Wilkinson 2008). In the context of hospital treatment, ethnic group density could also influence ethnic or cultural consonance between patients and providers, which has been shown to influence

communication, interaction, and perceived quality of care (Saha *et al*. 1999), and could also potentially affect how patients respond to treatment they perceive as lacking respect.

Table 5. National and city populations and ethnic groups affected by sickle cell disease

	United States[1]	Baltimore, MD[1]		United Kingdom[2]	London, UK[3]
Total population	304,059,724	637,000	Total population	58,789,194	7,428,600
African American	39,058,834	402,000	African/Caribbean/other	1,148,738	809,000
(% of total)	(12.8%)	(63.1%)	'Black' (% of total)	(2.0%)	(10.9%)
			Caribbean	565,876	334,400
			(% of total)	(1.0%)	(4.5%)
			African	485,277	412,500
			(% of total)	(0.8%)	(5.6%)
			Other 'Black'	97,585	62,100
			(% of total)	(0.2%)	(0.8%)

1. U.S. Census Bureau (2008).
2. Office for National Statistics (2001).
3. Office for National Statistics (2007).

Table 6 shows that SCD prevalence is lower among African Americans in the U.S.A. than among African and Caribbean ethnic groups in the U.K. The lower SCD prevalence among African Americans in the U.S.A., combined with the fact that African Americans in Baltimore make up a larger proportion of the national or city population than Black people in London, means that, in Baltimore, SCD patients are a *smaller* proportion of an ethnic group that is *larger*, relative to the total population. In London, by contrast, SCD patients make up a *larger* proportion of a *smaller* ethnic minority group. This could potentially influence pain coping and concern-raising behaviors. For example, higher concentrations of SCD patients within affected ethnic communities could lead to better learning and transmission of skills for coping and negotiating healthcare, and more access to role models in living with SCD.

Table 6. SCD prevalence per 1,000 among affected ethnic groups (in descending order)

United States[1]		United Kingdom[2]	
African American	2.5	African	14.7
Hispanic (Eastern U.S.)	0.898	Caribbean	5.6
Native American	0.362	Cypriot	0.496
Asian	0.0875	Indian	0.081
White	0.0172	White/Asian/Other	Insufficient data

1. Sickle Cell Disease Guideline Panel (1993).
2. Hickman *et al*. (1999).

Ethnic identity

Ethnic identity is the aspect of social identity that derives from a person's knowledge of membership of an ethnic group, together with the value and significance attached to that membership (Phinney 1992). Among African Americans in the U.S.A., a positive, affirmative ethnic identity has been associated with psychological health (Pillay 2005) and health behaviors

(Thompson and Chambers 2000). Among people with SCD in the U.S.A., having a self concept in which being African American was more central was associated with less severe pain and less use of healthcare services (Bediako *et al*. 2007). It is therefore possible that a stronger ethnic identity could lead to better psychological adjustment and wellbeing, enabling individuals to avoid painful episodes and self-manage SCD pain to a greater extent, leading to less use of hospital services for pain.

More research is needed, however, on ethnic identity among people with SCD, and how ethnic identity could influence specific aspects of coping with SCD, including communication and negotiation strategies in hospital. For example, patients with stronger ethnic identities might be less tolerant of perceived inequalities or injustices, leading to more disputes, conflicts, and concern-raising behaviors. Alternatively, they might be more effectively assertive in their interactions with healthcare providers, leading to fewer concern-raising behaviors. More research is also needed on how ethnic identity is influenced by ethnicity demographics and SCD prevalence, because the size of a person's ethnic group relative to the wider national or city population, and the numbers of other individuals with SCD in their community, could influence how they see themselves in relation to others. Studies that helped us to understand how ethnic identity is influenced by contextual factors like ethnicity demographics and SCD prevalence, and how ethnic identity influences interactions with healthcare providers and behaviors in hospital, would take us closer to understanding the complex pathways through which socio-cultural context influences healthcare outcomes.

Behavioral factors

Behavioral factors, including attitudes, beliefs, judgments and decision making, are important because they must mediate any socio-cultural, socio-political, and socio-economic influences on treatment outcomes, and may offer opportunities for interventions to improve treatment outcomes. There is considerable evidence of negative provider attitudes associated with under-treatment of SCD pain (Haywood *et al*. 2009). For example, when hospital healthcare providers rated recently encountered SCD patients, in over two-thirds of cases they believed patients were at least a little likely to exaggerate their discomfort, fail to comply with medical advice, abuse drugs, or manipulate providers (Ratanawongsa *et al*. 2009).

Some negative provider attitudes and behaviors towards SCD patients may reflect wider socio-political and socio-economic factors associated with racism and discrimination. Socio-economic factors may be especially important, because they may account for much ethnic inequality in health more generally (e.g., Cooper 2002), and because hospital provider attitudes were more positive about SCD patients with more education and those with employment, as well as those with less frequent hospitalizations and those without histories of disputes with staff about pain or analgesia (Ratanawongsa *et al*. 2009).

Other provider attitudes may be less closely related to wider socio-political and socio-economic factors, and result from misperceptions and misjudgments that have been observed in contexts without an ethnic dimension. Two behavioral factors could influence negative staff attitudes towards patients with SCD-related pain in ways that provide specific targets for interventions, whether or not they are related to wider racism and discrimination. These are misperceptions about patients' addiction to pain medication, and misjudgments about emotionally distressed patients with pain.

In national surveys of hospital providers in the U.S.A., many gave incorrectly high estimates of the proportions of SCD patients addicted to pain medication (Shapiro *et al*. 1997). One study of U.K. SCD patients showed that only two percent met authentic criteria for substance dependence, whereas almost one-third behaved in ways that could be misperceived or misinterpreted as substance dependence (Elander *et al*. 2003), and those behaviors were associated with concern-raising behaviors (Elander *et al*. 2004). When hospital providers rated descriptions of fictional SCD patients with different patterns of pain behavior and analgesic use, they differentiated genuine addiction from pain behaviors that merely resembled addiction when they assessed whether patients were addicted, but not when they assessed patients' analgesic needs (Elander *et al*. 2006). These studies seem to suggest that providers' misperception of patients' pain behaviors as signs of analgesic addiction could play a key role in the under-treatment of SCD pain.

Healthcare providers may also misperceive or misjudge SCD patients who express pain-related emotional distress. Negative emotional responses to pain among people with SCD predicted greater activity reductions and longer and more frequent hospitalizations (Gil *et al*. 1992), so patients with pain-related emotional distress may be those most in need of sympathetic and sensitive care. Presentations of emotional distress may bias providers against treating patients sympathetically, however, for when internists viewed videotaped presentations of chest pain (not SCD pain), their choices of diagnostic approach were more favorable to patients presenting pain in a 'businesslike' rather than a 'histrionic' manner (Birdwell *et al*. 1993). Chronic pain patients who were 'sensitive to socially desirable responses' presented high levels of pain and disability but low levels of distress, whereas those who were less sensitive to social desirability presented lower levels of pain and disability but higher levels of distress (Deshields *et al*. 1995).

Pain-related emotional distress could therefore be a characteristic of SCD patients who most need sensitive and sympathetic care, yet are most at risk of disrespectful and mistrustful treatment by providers, and may be a factor in the negative experiences reported by patients in hospital. Helping providers avoid treatment biases against emotionally distressed SCD patients with pain would therefore be a worthwhile target for behavioral interventions.

A model of influences on concern-raising behaviors

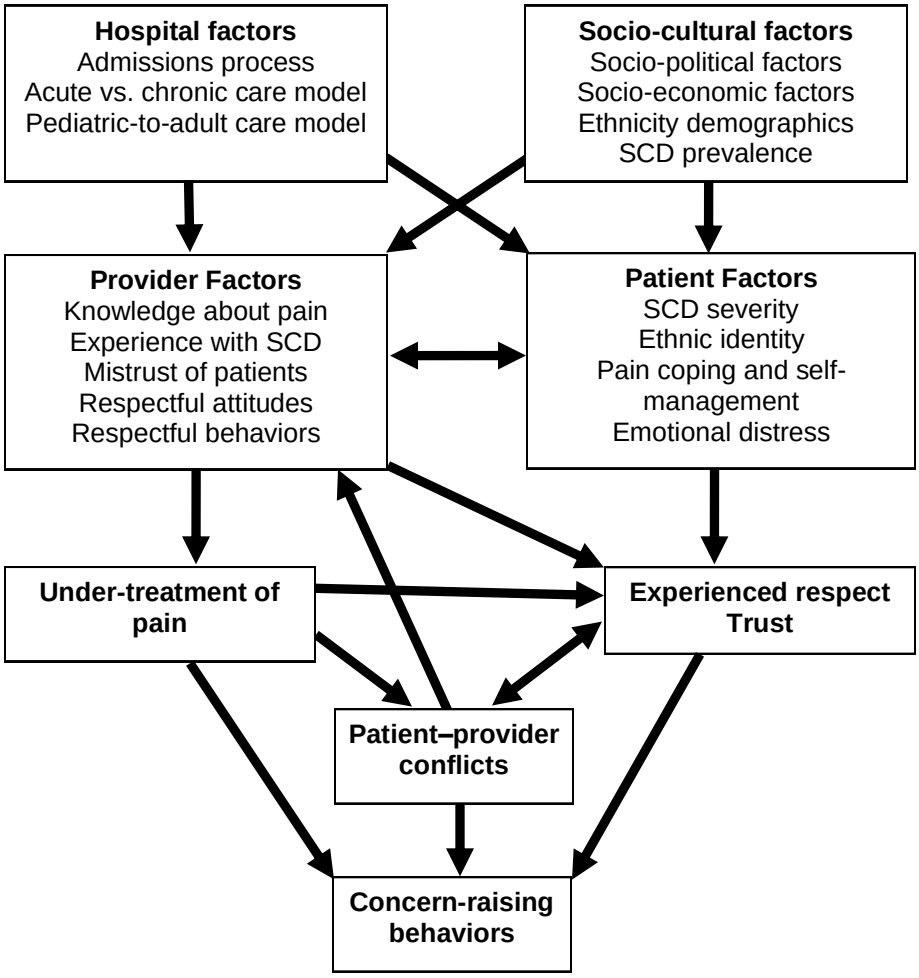
The factors influencing respect, trust, and concern-raising behaviors would not be expected to have simple independent effects; many could mediate and/or moderate others in complex pathways of influence. A theoretical model is therefore needed to integrate findings and guide hypothesis testing.

In a model proposed to explain findings from qualitative research, mistrust of SCD patients makes providers exert excessive control over pain management, which undermines patients' self-knowledge, self-reliance, and trust in providers. This leads to important aspects of patients' experiences of pain and pain management not being discussed (for example, social and psychological influences on pain, symptoms of analgesic dependence, and other side effects of medication), causing more frequent and/or prolonged hospital admissions (Maxwell *et al*. 1999).

That model is highly plausible and consistent with qualitative findings, but takes provider mistrust as a starting point. In figure 2, we present a preliminary model which sets providers' and patients' attitudes and behaviors in a wider context and attempts to explain the

pathways leading to concern-raising behaviors. The model is intended as a stimulus to further research and development of good clinical practice, rather than a complete description of processes and mechanisms. In this model, hospital and socio-cultural factors provide the broad context of individual attributes and behaviors. This includes aspects of the hospital-level organization and delivery of healthcare, and the social, cultural, political and economic aspects of the society in which patients and providers live and work, as well as local, area and national ethnicity demographics and SCD prevalence. Those contextual factors influence the attitudes, beliefs, and behaviors that both providers and patients bring to the clinical encounter. The degree of respect and trust expressed by providers, and the manner of presentation of pain by patients, then influence patient-provider interactions, in which the key elements influencing concern-raising behaviors are under-treatment of pain, patients' experienced respect and trust, and patient–provider conflicts about pain and its management.

Figure 2. A preliminary model of influences on concern-raising behaviors



An agenda for SCD research on respect and trust

Research of different types and in different settings will be needed to inform efforts to improve hospital pain management for SCD by increasing respect and trust. We therefore conclude this paper by proposing an international, interdisciplinary research agenda focusing on respect and trust. These are the key areas where we believe research can make a significant contribution:

1. International comparative studies

To obtain a fuller picture of the ways that socio-cultural factors influence patient and staff behaviors, data is needed from a wide range of socio-cultural settings, including those where the ethnic demography and SCD prevalence are different from the U.S.A. and U.K. Comparisons between separate studies in different settings are useful, but the most valuable insights will come from direct comparative analyses employing the same methods across settings. This means more international collaborations, using the same sampling and measurement strategies. A key focus in such studies might be the potential role of ethnic identity in linking wider socio-cultural factors with individual attitudes, beliefs, and behaviors.

2. Refinement of explanatory models

Theory in this area is at a very early stage, and models like the one proposed in figure 2 are really just preliminary sketches. Developing models like these is challenging because they need to span several disciplines, including behavioral medicine, sociology, and psychology. Theory and models are important, however, because they help with the integration and interpretation of diverse findings, so we would like to see more research on SCD pain management that tests hypotheses derived from theoretical models. Given the interdisciplinary nature of such models, it is highly unlikely that any single study would be able to fully test a model like that proposed in figure 2, but tests of limited parts of a model are also valuable for refining constructs, identifying mechanisms, and specifying causal pathways.

3. Effects of healthcare policies and structures on patients' and providers' experiences

Understanding behavior within institutional structures and processes is a key issue for improving pain management in SCD. The most important patient and provider behaviors occur in hospitals, which are large, highly structured, rule-governed institutions that shape and constrain individuals' behavior. Decisions about how healthcare is organized, paid for, and delivered influence the context of individual experiences and behaviors, with far-reaching implications for quality of care. We would therefore like to see more research on the implications of healthcare policy and management for the quality of hospital pain management as experienced by SCD patients.

4. Developmental and interpersonal processes

Managing pain involves assessment, judgment, decision making, and treatment, followed by monitoring and appraisal, and modification where necessary. The key influences – patient and provider attitudes, beliefs, and behaviors related to respect and trust – develop over time as a result of learning and experience, and the quality of pain management reflects the outcome of interpersonal interactions. Understanding the dynamics of those developmental and

interpersonal processes is therefore a key part of improving respect and trust, so we would like more research on how attitudes, beliefs, and behaviors related to respect and trust develop, and how patients and providers interact with one another as respect and trust grow, or fail to grow, or break down.

5. Applications of social psychology theory

Some parts of our model lend themselves to applications of attribution theory, which focuses on people's' beliefs about the causes of their own and others' behavior. In one model of helping behavior, attributions about responsibility influence feelings of sympathy or anger, which in turn influence intentions to help a person in need (Weiner 1980). Attribution theory has been used in research on contextual influences on provider judgments about patients with chronic pain (such as low back pain), but not to our knowledge in research on respect, trust, and hospital management of SCD pain.

Other potentially relevant areas of social psychology theory include categorization theory, stereotype activation theory, and theories about in-group and out-group perceptions and beliefs. These could be applied to the ways that SCD patients are perceived by themselves and others, and how those perceptions are affected by the relative size of groups and sub-groups, as explored earlier in the paper.

6. Development and evaluation of interventions to improve respect and trust

For research to contribute to improving SCD patient care, interventions to improve respect and trust must be developed and evaluated. These could be transferable, low-intensity interventions, like the short film about patient experiences that improved provider attitudes (Haywood *et al*. 2011), or more embedded interventions, like the training programme that addressed provider fears about patients' addiction to prescribed analgesics (Brookoff and Polomano 1992). They could also include patient education programs about communicating pain to providers and negotiating treatment for pain in ways that facilitate respect and trust.

Key messages

- Respect and trust are powerful concepts that integrate diverse strands of research and practice, and can be a lever to improve patients' experiences and the outcomes of hospital treatment.
- Improving respect and trust in the treatment of SCD pain should be a priority for healthcare providers, managers, and researchers.
- Collaborative, international, and interdisciplinary research can help to improve the treatment of SCD pain by identifying ways to increase respect and trust.

Acknowledgement

The authors are grateful to the editors and reviewers for their helpful comments on previous drafts.

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